

# SJLIFE

## Men's Health Questionnaire

The following questionnaire addresses personal subject matter on topics including fertility, puberty, and sexual health/functioning. These important quality of life issues have not been well studied among survivors of childhood cancer. By completing this questionnaire, you will help us better understand these issues which could one day lead to improved prevention and treatment options.

All adult SJLIFE participants are being asked to complete this questionnaire. Be assured that your participation is voluntary and you may choose to answer all, some, or none of the questionnaire items. Your responses will be kept confidential so please do not put any identifying information (like name, age, or date of birth) on this questionnaire. Once completed, please seal the questionnaire in the attached envelope and drop it off in the questionnaire box in the SJLIFE clinic. Thank you in advance for your participation.

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Please! Do not mark below this line

## INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box.
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided.
5. Once you have completed the questionnaire, please place it in the attached envelope and drop it off in the SJLIFE questionnaire box in clinic.

## TESTOSTERONE THERAPY

Testosterone is the male hormone made in the testes. It can be given to patients to start puberty (puberty is defined as the physical changes that allow a boy's body to change into a man's body) or can be used in older males who have low blood levels of testosterone.

**A1. Have you ever been treated with testosterone?**

- Yes
- No → **Go to Question B1, next page.**
- I don't know

**A2. Were you treated with testosterone therapy during puberty (puberty in boys is typically around age 11 and leads to increase in size of the testes, growth of the penis, development of pubic hair, underarm hair and facial hair)?**

- Yes
- No
- I don't know

**A3. Was your treatment with testosterone...**

- continuous
- interrupted (stopped and started again)

**A4. How many years (in total) have you been on testosterone? Do not count years in which your testosterone therapy was stopped.**

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Years

**A5. Are you currently on testosterone?**

- Yes
- No

**A6. How have you received testosterone treatments? (Mark all that apply)**

- Injections (shots)       Skin Patch
- Pills                               Inside the mouth patch
- Gel                                  Suppository

**A7. At what age did you start testosterone?**

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Age in years

**A8. If you took testosterone and it was discontinued, at what age did you last stop taking testosterone?**

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Age in years

**A9. If you stopped taking testosterone, why did you stop? (Mark all that apply)**

- I stopped the medicine because I did not like taking it
- My doctor told me to stop
- I no longer had a prescription for the medicine
- Other reason

*If Other reason, explain.*

**BODY IMAGE**

On this scale you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and mark the response which comes closest to the way you have been feeling about yourself during the past week.

		Not at all	A little	Quite a bit	Very much
<b>During the <u>past week</u> . . . .</b>					
B1. Have you been feeling <u>self-conscious</u> about your appearance? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B2. Have you felt <u>less</u> physically attractive as a result of your disease or treatment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B3. Have you been <u>dissatisfied</u> with your appearance when dressed? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B4. Have you been feeling <u>less</u> masculine as a result of your disease or treatment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B5. Have you been finding it <u>difficult</u> to look at yourself naked? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B6. Have you been feeling <u>less</u> sexually attractive as a result of your disease or treatment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B7. Have you been <u>avoiding</u> people because of the way you felt about your appearance? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B8. Have you been feeling the treatment has left your body <u>less</u> whole? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B9. Have you felt <u>dissatisfied</u> with your body? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B10. Have you been <u>dissatisfied</u> with the appearance of a scar(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>B11. At the present time, do you have any of the following?</b>		No			Yes
Persistent hair loss. . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Scarring or disfigurement of the head or neck region (including the face). . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Scarring or disfigurement of the chest or abdominal region. . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg). . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Walk with a limp. . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Loss of an arm or a leg . . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Loss of an eye . . . . .	<input type="checkbox"/>		<input type="checkbox"/>		
Other. . . . .	<input type="checkbox"/>		<input type="checkbox"/>		

*If Other, specify.*

# PERCEPTIONS

It is common for people to have different ideas about their own chances of experiencing certain medical problems. Please answer the next few questions by marking the answer that best describes your own opinions.

**C1. Mark the response that best describes your risk compared to other men your age never diagnosed with cancer or a disease like cancer.**

	Much less	Slightly less	About the same	Slightly more	Much more
a. Infertility . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Low testosterone levels . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Sexual dysfunction . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If you answered *Slightly more* or *Much more* to any of the medical problems listed above, continue with the next question. Otherwise, skip to Question D1, next page.**

**C2. If you think you have increased risk (you answered *Slightly more* or *Much more* in Question C1) for having any of the medical problems in Question C1, please mark the reasons you think you are at increased risk from the choices below. If you do not feel that you are at increased risk for a medical problem, mark "Not applicable".**

I think I am at increased risk because of . . .  
(Mark all that apply)

	The kind of surgery I needed for my cancer or similar illness	The kind of radiation I received	The kind of chemotherapy I received	The type of cancer or an illness like cancer that I had	Not applicable
a. Infertility . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Low testosterone levels . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Sexual dysfunction . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**C3. If you consider yourself at risk for infertility, low testosterone, and/or sexual dysfunction, how did you learn of your increased risk? (Mark all that apply)**

	Not applicable	Your oncologist	Your family	Your general practitioner/internist	Information you found on the internet	Another way
a. Infertility . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Low testosterone levels . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Sexual dysfunction . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If another way, please specify.*

**C4. If told by a healthcare professional about potential problems with fertility, low testosterone levels, and/or sexual functioning, when did you receive the information? (Mark all that apply)**

	Not applicable	At the time of diagnosis	At the time of treatment	After treatment, by your oncologist	After treatment in a long-term follow-up program/cancer survivor program	After treatment in another setting
a. Infertility . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Low testosterone levels . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Sexual dysfunction . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If in another setting, please specify.*

## RELATIONSHIP/MARITAL SATISFACTION SCALE

D1. Are you currently married or in a significant relationship?

Yes

No → **Go to Question E1.**

Please mark the number for each item which best answers that item for you.

D2. How well does your partner meet your needs?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poorly		Average		Extremely well

D3. In general, how satisfied are you with your relationship?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unsatisfied		Average		Extremely satisfied

D4. How good is your relationship compared to most?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor		Average		Excellent

D5. How often do you wish you hadn't gotten into this relationship?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Never		Average		Very often

D6. To what extent has your relationship met your original expectations?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hardly at all		Average		Completely

D7. How much do you love your partner?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not much		Average		Very much

D8. How many problems are there in your relationship?

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very few		Average		Very many

## FERTILITY AND FERTILITY PRESERVATION

The next set of questions will ask about your fertility, pubertal development, sexual development, and quality of life. You may feel these questions are personal. Please be reassured your responses will remain confidential.

E1. Do you know your fertility status?

Yes

No

E2. Have you and a partner ever tried to become pregnant?

Yes

No → **Go to Question E14, next page.**

E3. Has a female partner ever had difficulty (it took more than 1 year) becoming pregnant by you?

Yes  No  I don't know

E4. Were you able to have all the children you wanted to have?

Yes → **Go to Question E6, next page.**

No

E4a. If no, which of you wanted more children?

- I wanted more children but my partner(s) did not
- My partner(s) wanted more children but I did not
- We both wanted more children but we could not have more

E5. If more children were wanted, what were the reasons for not having more children? (*Mark all that apply*)

- I was unable to father more children (male infertility)
- I had other health issues related to my cancer treatment that made us decide not to have more children
- I had other health issues not related to my cancer treatment that made us decide not to have more children
- My partner was not able to become pregnant (female infertility)
- My partner had other health issues that made us decide not to have more children
- My partner and I tried but could not become pregnant, we do not know the reason why
- There were issues other than health that kept us from having more children (social/financial)

*If there were other issues, please specify.*

E6. Do you have any concerns about your fertility (your ability to have/produce biological children in the future)?

- No
- Yes
- Not sure

E7. Have you or a female partner ever been evaluated for infertility?

- Yes
- No → **Go to Question E11.**
- I don't know

E8. If you or your partner were evaluated for decreased fertility, was a problem identified?

- Yes. A fertility problem was found in my partner.
- Yes. A fertility problem was found in me.
- Yes. A fertility problem was found in both me and my partner.
- No
- I don't know

E9. Were you personally evaluated by a fertility specialist?

- Yes
- No → **Go to Question E11.**

*If yes, which kind of physician?*

*If yes, how old were you at the time of evaluation?*

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Age in years

E10. If you were evaluated by a fertility specialist was a problem identified?

- Yes
- No

*If yes, please specify.*

E11. Have you ever had semen (sperm) analysis?

- Yes
- No → **Go to Question E14.**
- I don't know

E12. On your last semen analysis was your sperm count . . .

- Normal
- Low
- Zero → **Go to Question E14.**
- I don't know

E13. On your last semen analysis was the motility (movement) of your sperm . . .

- Normal
- Low
- Zero - my sperm was not moving at all
- I don't know

E14. Were you offered preservation of your sperm by freezing or banking before you started cancer treatment?

- Yes
- No → **Go to Question F1, page 8.**
- I don't know

E15. Did you choose to freeze or bank your sperm?

- Yes
- No → **Go to Question E21, next page.**
- I don't know

**E16. Have you tried to use your frozen/banked sperm to fertilize an egg or have a child?**

- Yes
- No → **Go to Question E20.**
- I don't know → **Go to Question F1, next page.**

**E17. How many times have you tried to use your frozen/banked sperm?**

- 1 time
- 2-5 times
- > 5 times

**E18. How many times has a pregnancy resulted from the use of your frozen/banked sperm?**

- None have resulted       Three times
- Once                               More than three times
- Twice

**E19. How many babies have been born from use of your frozen/banked sperm?**

- None have resulted       Three
- One                               More than three
- Two

**E20. If you did not use your frozen/banked sperm, why did you decide not to use them? (Mark all that apply)**

- I did not know how to use the banked sperm
- I was worried about my health and my ability to be a father
- I was worried about passing on cancer to my child
- I was worried about having a child damaged by my cancer
- I was worried about having a child damaged by my cancer treatment
- It was too expensive
- I did not believe it was the right thing to do
- I'm not yet ready to have children
- Was able to father a child naturally
- Still plan to use it in the future
- Other reason

*If Other reason, please specify.*

**E21. If you did not choose to freeze/bank your sperm, why did you decide not to? (Mark all that apply)**

- I was too young at the time of diagnosis
- I did not know how to freeze/bank sperm and could not find out how to do it
- I was worried about passing on cancer to my child
- I was worried about having a child damaged by my cancer
- I was worried about having a child damaged by my cancer treatment
- Sperm freezing/banking was too expensive
- I had no desire for children or additional children
- My doctors did not think that my cancer treatment would cause infertility
- I did not think that cancer treatment would cause infertility
- I was too sick to complete sperm freezing/banking procedures at the time of my cancer diagnosis
- I don't know why I did not pursue sperm freezing/banking
- I was told that my sperm count was too low
- I had religious concerns about sperm freezing/banking
- I had moral concerns about sperm freezing/banking
- My parents advised against it
- Other reason

*If Other reason, please specify.*

## PUBERTY AND SEXUAL DEVELOPMENT

F1. Was the onset of your puberty . . . (The onset of puberty in males is characterized by development of pubic hair, increase in size of testes and increase in size of penis.)

- Early compared to others your age
- Normal compared to others your age
- Late compared to others your age

F2. Were hormones needed to start your puberty?

- Yes
- No

F3. Have you ever ejaculated? (Ejaculation is the ejecting of semen from the penis. Ejaculation may occur during intercourse, masturbation or spontaneously during sleep - a nocturnal emission or "wet dream".)

- Yes
- No

If yes, at what age did you first ejaculate?

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Age in years

F4. Have you had sexual intercourse?

- Yes
- No

If no, Go to Question F7.

If yes, at what age did you first have intercourse?

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Age in years

F5. Did you or your partner use a condom at last intercourse?

- No
- Yes

Go to Question F6.

F5a. If you did not use a condom at last intercourse, what method did you or your partner use to prevent pregnancy? (Select only one response.)

- No method was used to prevent pregnancy
- Birth control pills
- IUD (such as Mirena or ParaGard)
- Implant (such as Implanon or Nexplanon)
- Shot (such as Depo-Provera)
- Birth control patch (such as Ortho Evra)
- Birth control ring (such as NuvaRing)
- Sponge (such as Today Sponge)
- Spermicide
- Withdrawal or some other method

F6. In general, how often do you or your partner use a condom during sex? (Select only one response.)

- Not applicable because I have never had sex
- Never
- Rarely
- Sometimes
- Often
- Always

F7. My previous sexual experiences have been with . . . (Mark all that apply)

- The opposite gender - women
- The same gender - men
- Both genders- women and men
- Myself- I have masturbated
- None of the above
- No reply

F8. My sexual experiences in the last year have been with . . . (Mark all that apply)

- The opposite gender - women
- The same gender - men
- Both genders- women and men
- Myself- I have masturbated
- None of the above
- No reply



F9. How many sexual partners have you had in the last month?

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F10. How many sexual partners have you had in the last year?

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F11. How many sexual partners have you had in your lifetime?

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## SEXUAL ACTIVITY

The following are questions commonly used by doctors to assess sexual function in males. They are standardized questions asked in a standardized fashion.

These questions are sensitive and personal. They are very important in understanding how your medical illness or treatment affects yourself and your body. Some questions ask about your own experiences, thoughts, and feelings, while others ask about how treatment has affected your intimate relationships. Please answer each question honestly and accurately. Be assured that your responses are totally confidential.

G1. Have you been sexually active in the past year (alone or with a partner)?

Yes → **Go to Question G3.**

No

G2. I have not been sexually active in the last year because . . .  
(Mark all that apply)

I have never been sexually active

→ **Go to Question G4, next page.**

I am too tired

I am not interested

I have a physical problem that makes sexual relations difficult or uncomfortable

My partner is not interested

My partner is too tired

My partner has a physical problem that makes sexual relations difficult or uncomfortable

Other

*If Other, please specify.*

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G3. Have you been sexually active in the past month (alone or with a partner)?

Yes

No

**G4. In the past month, how frequently have you had sexual thoughts, urges, fantasies, or erotic dreams? (Please mark the one item that is closest to your experience.)**

- Not at all
- Once
- 2 or 3 times
- Once a week
- 2 or 3 times a week
- Once a day
- More than once a day

**G5. Using the scale below, how frequently have you felt an interest or desire to engage in the following specific activities in the past month?**

*(This question is about your desire to engage, not about how you feel during sexual activity.)*

**(For each item, please mark the response that is closest to your experience):**

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Masturbation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Touching, hugging, holding, kissing . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Petting or foreplay . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Intercourse (penetration with a partner) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other sexual activity . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If Other, please specify.*

**G6. How frequently have you become aroused by the following sexual activity in the past month?**

*(By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexual.)*

**(For each item, please mark the response that is closest to your experience):**

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Masturbation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Touching, hugging, holding, kissing . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Petting or foreplay . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Intercourse (penetration with a partner) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other sexual activity . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If Other, please specify.*

**G7. In the past month, have you felt pleasure from any sexual activity?**

- I have had no sexual activity in the past month
- I have not felt any pleasure
- Seldom, less than 25% of the time
- Sometimes, about 50% of the time
- Usually, about 75% of the time
- Always felt pleasure

**G8. Using the scale below, how frequently have you engaged in the following activities in the past month?**

*(For each item, please mark the response that is closest to your experience):*

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Masturbation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Touching, hugging, holding, kissing . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Petting or foreplay . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Intercourse (penetration with a partner) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other sexual activity . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If Other, please specify.*

**G9. In the past month, how often have you reached orgasm (ejaculation) during sexual activity?**

- I have had no sexual activity in the last month
- I have not experienced orgasm
- Seldom, less than 25% of the time
- Sometimes, about 50% of the time
- Usually, about 75% of the time
- I always experienced orgasm

**G10. When you have orgasms (ejaculations), how intense have they been in the past month?**

- I have had no sexual activity in the last month
- I have had no orgasms in the last month
- My orgasms were very mild
- My orgasms were fairly mild
- My orgasms were fairly strong
- My orgasms were very strong

**G11. How easy or difficult has it been for you to have orgasms (ejaculations) in the past month?**

- I have had no sexual activity in the last month
- I have had no orgasms in the last month
- It was very difficult to have orgasms; it took a long time and a lot of concentration
- It was fairly difficult; it took a while
- It was fairly easy
- It was very easy

**G12. How frequently in the past month have you had the problems listed below?**

**ALSO, MARK THE BOX IN THE LAST COLUMN if the problem stops your sexual activity.**

	Not at all	Seldom, less than 25% of the time	Sometimes, about 50% of the time	Usually, about 75% of the time	Always	Does the problem stop your current sexual activity?	
						Yes	No
a. Difficulty getting an erection. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Lack of sexual interest or desire. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Losing an erection during sexual activity. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Delayed ejaculation . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Anxiety about your sexual performance. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Unable to achieve orgasm. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Pain during penetration or intercourse. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Other problem with sexuality . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If Other, please describe.*

**G13. Please rate how interested you have been in sexual thoughts, feelings, or actions in the past month by marking a number from 0 to 10 (0=Not at all interested, 10=Extremely interested).**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0	1	2	3	4	5	6	7	8	9	10
Not at all Interested					Extremely Interested					

**G14. Please rate the extent to which sexual activity has been satisfying for you in the past month by marking a number from 0 to 10 (0=Not at all satisfying, 10=Extremely satisfying).**

- 0    1    2    3    4    5    6    7    8    9    10

Not at all Satisfying Extremely Satisfying

**G15. How often did the following factors influence your sexual activity in the past month?**

	Not at all	Sometimes, about 50% of the time	Usually, about 75% of the time	Always
a. My own health . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. My partner's health . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Conflict in my relationship . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Other . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If Other, please specify.*

**G16. Are you currently in a married or partner relationship that could be sexual?**

- NO, I do not have a possible partner → **Go to Question H1, next page.**
- YES, I am married or have a partner, and we HAVE been sexually active this past year
- YES, I am married or have a partner, but we HAVE NOT been sexually active this past year

**G17. Over the past 4 weeks, how frequently have you been able to communicate your sexual desires or preferences to your partner?**

- I have been unable to communicate my desires or preferences
- Seldom, less than 25% of the time
- Sometimes, about 50% of the time
- Usually, about 75% of the time
- I was always able to communicate my desires or preferences

**G18. Overall, how satisfied have you been with your sexual relationship with your partner?**

- Very dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Very satisfied

**G19. Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?**

- Very dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Very satisfied

**G20. Overall, how satisfied do you think your partner has been with your sexual relationship?**

- Very dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Very satisfied

**G21. Over the past 4 weeks, how satisfied do you think your partner has been with your sexual relationship?**

- Very dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Very satisfied

**G22. Over the past 4 weeks, please rate how satisfied you have been with your ability to share warmth and intimacy with your partner by marking a number below from 0 to 10 (0=Not at all satisfied, 10=Extremely satisfied).**

- 0    1    2    3    4    5    6    7    8    9    10

Not at all Satisfied Extremely Satisfied

**G23. Over the past 4 weeks, please rate how comfortable you have been with touching, hugging or holding your partner by marking a number from 0 to 10 (0=Not at all comfortable, 10=Extremely comfortable).**

0 1 2 3 4 5 6 7 8 9 10

Not at all  
Comfortable

Extremely  
Comfortable

**G24. I feel positive about my sexual relationship?**

- Not in a sexual relationship
- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**G25. I feel depressed about symptoms that keep me from enjoying sexual activity?**

- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**G26. I sometimes feel too distressed to engage in sexual activity?**

- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

**G27. Problems with my sexual performance cause me distress?**

- Rarely or none of the time
- Some or a little bit of the time
- Occasionally or a moderate amount of time
- All of the time

## ERECTILE FUNCTION

These questions are specifically about erectile function and are frequently used by doctors to determine adequacy of erectile function and patient response to erectile treatments. Questions H1 to H15 are in reference to the last 4 weeks . . .

*Please pick the single best answer*

**H1. In the past 4 weeks, how often were you able to get an erection during sexual activity?**

- No sexual activity → **Go to Question H11, next page.**
- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H2. In the past 4 weeks, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?**

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H3. In the past 4 weeks, when you attempted sexual intercourse, how often were you able to penetrate (enter) your partner?**

- Did not attempt intercourse → **Go to Question H9, next page.**
- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H4. In the past 4 weeks, during sexual intercourse, how often were you able to maintain your erection after you had penetrated (entered) your partner?**

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H5. In the past 4 weeks, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?**

- Extremely difficult
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

**H6. In the past 4 weeks, how many times have you attempted sexual intercourse?**

- One to two attempts
- Three to four attempts
- Five to six attempts
- Seven to ten attempts
- Eleven+ attempts

**H7. In the past 4 weeks, when you attempted sexual intercourse, how often was it satisfactory for you?**

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H8. In the past 4 weeks, how much have you enjoyed sexual intercourse?**

- No enjoyment
- Not very enjoyable
- Fairly enjoyable
- Highly enjoyable
- Very highly enjoyable

**H9. In the past 4 weeks, when you had sexual stimulation or intercourse, how often did you ejaculate?**

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H10. In the past 4 weeks, when you had sexual stimulation or intercourse, how often did you have the feeling of orgasm or climax?**

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H11. In the past 4 weeks, how often have you felt sexual desire?**

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always

**H12. In the past 4 weeks, how would you rate your level of sexual desire?**

- Very low/none at all
- Low
- Moderate
- High
- Very high

**H13. In the past 4 weeks, how satisfied have you been with your overall sex life?**

- Very dissatisfied
- Moderately dissatisfied
- About equally satisfied and dissatisfied
- Moderately satisfied
- Very satisfied

**H14. In the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?**

- Very dissatisfied
- Moderately dissatisfied
- About equally satisfied and dissatisfied
- Moderately satisfied
- Very satisfied

H15. In the past 4 weeks, how do you rate your confidence that you could get and keep an erection?

- Very low
- Low
- Moderate
- High
- Very high

### Erectile Dysfunction Therapy

Erectile dysfunction is a sexual problem characterized by the inability to develop or maintain an erection of the penis. Treatment for erectile dysfunction can include medicines taken by mouth, medicines that can be given as injections, mechanical devices like pumps, and surgery.

I1. Have you ever received treatment for erectile dysfunction?

- Yes
- No → **Go to Question J1, next page.**

I2. Have you ever been treated with a medicine for erectile dysfunction - like Viagra, Cialis, Levitra, Muse, Edex or Caverject?

- Yes
- No

*If yes, what medicine(s)?*

I2a. When did you begin treatment for erectile dysfunction?

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Month (mm)      Year (yyyy)

I2b. Are you currently on treatment for erectile dysfunction?

- Yes
- No

I3. Have you ever had surgery for erectile dysfunction?

- Yes
- No

*If yes, what surgery(ies)?*

I3a. Date of first erectile dysfunction surgery

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Month (mm)      Year (yyyy)

I4. Have you ever had other medical treatment for erectile dysfunction (e.g., mechanical pump)?

- Yes
- No

*If yes, what treatment(s)?*

I5. Have you ever tried/received complementary or alternative medical treatment (herbal supplements or acupuncture, for example) for erectile dysfunction?

- Yes
- No

*If yes, what treatments?*

I6. Have you ever received psychological treatment (talk therapy) for problems related to erectile dysfunction?

- Yes
- No

Finally a few questions about how you think survivors of childhood cancer and similar illnesses could best be informed about their risk (if any) of testicular or sexual dysfunction.

**J1. Is there anything you wish you had been told at the time of your diagnosis and treatment regarding your future fertility or testicular function or sexual functioning? (use additional pages if necessary)**

**J2. Is there anything you wish you had been told in a follow up cancer visit regarding your future fertility or testicular function or sexual functioning? (use additional pages if necessary)**

**J3. Is there anything you wish to know now regarding fertility or testicular or sexual functioning? (use additional pages if necessary)**

**We are always interested in your input.**

**Use this space for any additional comments you may have:**

**Thank you for participating.**